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Introduction

Developing an End of Life Plan

People make end of life plans for all sorts of reasons. Some people are concerned that one day they will become so sick and frail and their quality of life will become so impaired that death will become the preferred option. Others worry that because current generations are living longer than their parents' and grandparents' generations, they will have to face that new set of worries that come from longevity itself. Some elderly people are simply 'tired of life.'

The reasons that lead an elderly person or someone who is seriously ill to seek information about their end-of-life choices are many and varied. All are intensely personal. Rewriting the ways in which society can plan for and experience death and dying is the challenge of our time.

The development of an end of life plan is one small step that all of us can take to protect those we love from the ravages of the law. While most of us will never use our plan, we can all draw comfort in knowing that if things ever become too painful or undignified (especially in the context of serious illness and age), we will have a plan in place that will allow us to maintain our dignity and our independence.

The Wonders of Modern Medicine

In any discussion of end of life issues the role of modern medicine is paramount. While no one can be critical of the huge advances in medical science over recent decades - improving beyond measure the length and quality of our lives – there is also a flip side. In contrast to previous generations, we are now far more likely to die of slower, debilitating conditions that are associated with old age and illness. Yet we are also more likely to be kept alive through an increasingly sophisticated array of medical technologies.

A longer life can be a wonderful thing, but should we be forced to live on, if we come to a point where we have simply had enough? Surely the act of balancing one's quality of life against the struggle of daily living in our later years or in illness, should be each individual to arbitrate.

Our Ageing Population

A century ago when life expectancy was approximately 25 years less than it is today, few people had the opportunity to reflect on how they might die. Then people were much more likely to die quickly with little warning. For example, one hundred years ago infectious disease was common. People considered themselves lucky if they were still alive in their mid 50s. The widespread introduction of public health measures such as sewerage, water reticulation, good housing, and of course the introduction of modern antibiotics have all played a part in greatly reducing the toll of infectious disease.

In modern times, those living in the developed west have a life expectancy of 75 to 80 years. Now in industrialised countries, we will be more likely to experience diseases and disabilities that were rare in earlier times. While old age is not in itself predictive of serious physical illness, the gradual deterioration of one's body with age leads to an almost inevitable decline in a person's quality of life.

This is why we see the issue of control in dying as being an increasingly common concern for many elderly people. Exit's workshop program is often booked out months ahead as elderly folk seek answers to their practical questions about their end of life options. Although few who attend these workshops have any intention of dying in the near future, most see a need to organise and plan for this inevitable event.

Just as many of us plan for other aspects associated with dying (eg. we all write a will, appoint executors, and some of us prepay for funerals), so it is common sense to ensure that we have a plan about how we might wish to die. Yet to be in a position to plan for one's death, one must first know one's options. And that means information.

The Question of Suicide

Anyone who makes plans for their own death can be said to be planning their own suicide. While for some people suicide is a tainted concept, for a growing number of older people it is an issue of great interest and discussion. In this context, suicide is a way out of a life that an individual might consider is not worth living.

People who come to Exit workshops are well aware of the importance of making that ultimate of decisions, the decision to die. They are all acutely aware of the need to get it right. In this Chapter, we examine the phenomenon of suicide in the context of the modern life course, and why access to the best in end of life information is so important.

A Brief History of Suicide

Over the years, the way in which society views the taking of one's own life has varied enormously. Suicide has not always been seen as the act of a sick and depressed person. In ancient Greece, Athenian magistrates kept a supply of poison for anyone who wanted to die. You just needed official permission. For the Stoics of ancient times, suicide was considered an appropriate response, if the problems of pain, grave illness or physical abnormalities became too great.

With the rise of Christianity, however, suicide came to be viewed as a sin (a violation of the sixth commandment). As Lisa Lieberman writes in her book *Leaving You*, all of a sudden 'the Roman ideal of heroic individualism' was replaced 'with a platonic concept of submission to divine authority'.

It was Christianity that changed society's view of suicide from the act of a responsible person, to an infringement upon the rights of God. One's death became a matter of God's will, not one's own and it was at this point that penalties were first established for those who attempted suicide. If the suicide was successful, it was the family of the offender who were punished with fines and social disgrace.

With the emergence of modern medicine in the 19th Century, the meaning of suicide changed again and it is this understanding that prevails today. Suicide is now generally thought of as an illness. If a person wants to end their life, then they must be sick (psychiatric illness, with depression the usual diagnosis). The appropriate response, therefore, is medical treatment (in the form of psychiatric counselling and/or anti-depressant medications).

At Exit International, we question the view of suicide that automatically links a person's decision to die to depression and mental illness. Are we seriously postulating that the suicide bombers of the Middle East are depressed? Rather, the act of suicide must be seen as context dependent.

For example, a person who is very elderly and who is seeing friends die around them on a weekly basis and who must be wondering 'am I next?' is going to have a very different outlook on dying than the young person who has their whole life in front of them. Likewise, when serious illness is present. A person's attitude towards death must be understood in the context of that person's situation.

In Oregon, where physician-assisted suicide (PAS) is legal, symptoms of depression have been found in 20 per cent of patients who request PAS (Battle, 2003). A 1998 Australian study reported 15 per cent of men and 18 per cent of women who suicided had 'an associated or contributory diagnosis of a mental disorder' (ABS, 2000). At Exit we argue that feelings of sadness (as opposed to clinical depression) are a normal response to a diagnosis of a serious illness.

This is why some studies continue to find a sadness associated with a serious illness. You don't need to be a psychiatrist

to understand that this might be a normal response to an extraordinary situation (Ryan, 1996). To assume that suicide amongst the elderly or people who are seriously ill is the result of depression or other psychiatric illness, is to adopt uncritically a biomedical way of seeing the world. We can do better.

Suicide & Depression

The link between suicide and depression remains a vexed issue with millions of dollars in government funding devoted to raising the community's awareness of suicide, especially amongst the young and some minority groups (eg. farmers). And there can be no doubt. People who suffer from clinical depression are clearly at risk of suicide. Severe depressive states can rob a person of the ability to make rational decisions and these people need care and treatment until they are once again able to resume control. Yet illness of this severity is not common and needs to be distinguished from a larger group of people who show occasional signs of depression but who are in full control of their actions.

There is a significant difference between a person having moments of feeling down or having a transitory feeling that their life has lost purpose and the person who has severe clinical depression, where even the most basic daily decisions of life become problematic.

This is quite different from an elderly or seriously ill person's desire to formulate an end of life plan; a plan whose sole aim is to maintain control over their final days. People who like to be prepared and who are not depressed should not be viewed in psychiatric terms.

End of Life Decisions & the Role of Palliative Care

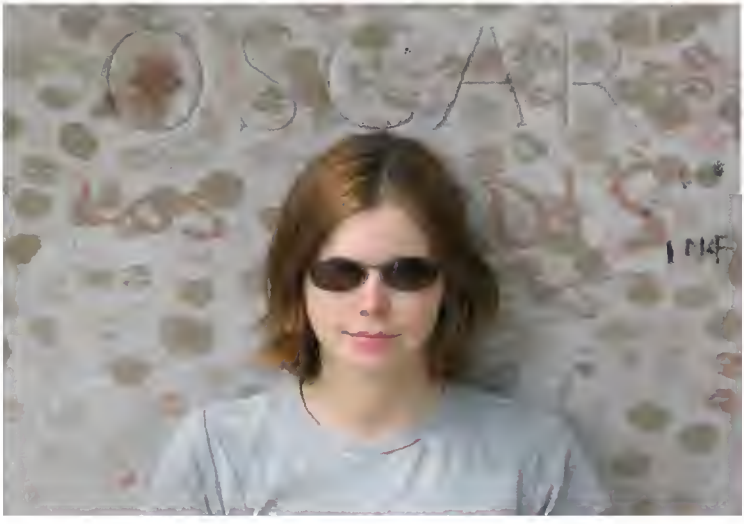
Critics of Assisted Suicide often argue that if palliative care is available and of good enough standard, patients will never need ask for assistance to die. This is untrue, but to understand the claim, one needs to look at the background of the palliative care speciality.

Palliative care was the first branch of medicine to shift the focus away from 'cure at all costs' and to focus instead upon the treatment and management of symptoms (for people who have a life-threatening illness). In this sense, palliative care's aim has never been 'cure'. Rather, palliative medicine is about symptom control. It is about improving the quality of life of those who are seriously ill and dying.

To date, palliative care has been most successful in the treatment of pain. Indeed, it is often claimed - perhaps exaggeratedly - that palliative care can successfully address pain in 95 per cent of all cases. What is much less spoken about is the speciality's limited ability to alleviate some other common symptoms of serious disease; symptoms such as weakness, breathlessness or nausea. Or, quite simply to guarantee a good death.

No where can the shortcomings of palliative care be more obvious than in the tragic death in August 2008 of 31 year old writer, Angelique Flowers. At the age of 15 years, Angelique was diagnosed with painful Crohn's Disease. On 9 May 2008, shortly before her 31st birthday she was diagnosed with Stage 4 colon cancer.

As Angelique said, in one of the several videos she made in the weeks leading up to her death, there is no Stage 5. At Stage 4 and upon diagnosis, the cancer had already spread to her liver and



Angelique Flowers at Oscar Wilde's grave at Pere Lachaise cemetery in Paris in 2006.

ovaries. Angie's doctors told her then, her days were numbered. They also told her that there would be very little they could do to ensure that her death was pain-free and dignified.

As history now tells Angelique's story, this courageous, clever, beautiful young woman died in the most difficult and unpleasant way. As a young palliative care patient she received the best that modern medicine can provide, and that money can buy. Despite some hiccups, Angelique's pain control was described as reasonable. What was not so good and what the law prevents medicine from addressing, was her death.

Angelique Flowers wanted control over her death. Because she knew her death could come fast and it was unlikely to be peaceful. As it happened, Angelique died vomiting up faecal matter after experiencing an acute bowel blockage. Just as her doctors had warned, her death was simply awful. They had told her that it could be shocking, and it was. Her brother Damian held her in his arms through this awful ordeal.

This young woman had been terrified of this possibility which is why she put out a call for Nembutal, on the Internet. Successful at obtaining Nembutal, because of the law she kept the drug hidden at her parents' home. When the bowel blockage occurred, Angelique was in the hospice yet her Nembutal was at home. She lost her chance to take control.

Shortly before she died, Angie made a video diary. In it she pleaded with Australia's Prime Minister, Kevin Rudd, to once again, legalise voluntary euthanasia in Australia. Angelique's tragic story shows many things, including why a modern, civilised society needs the best palliative care and voluntary euthanasia/ assisted suicide. Her story is told in the feature documentary '35 Letters' which won the 2015 Sydney Film Festival.

See: *https://www.youtube.com/watch?v=5DqXGLwmJsc*

At Exit, we are frequently approached by people who tell us that their palliative care is the best. But, like Angelique, they still wish to be in control of their death. They say that while they might not be in pain right now, the quality of their life is nonetheless seriously affected by their illness. They know that there is often nothing that modern palliative medicine can do about it.

Some of these people are so weak that they cannot move unassisted. Others have shortness of breath which makes independent living impossible. For a significant number of people, it is non-medical issues that have most impact upon the quality of their life.

One memorable case concerned a middle aged man called Bob. Bob was suffering from lung cancer. He was incredibly sad that his favourite past time - a round of gold with his mates - was no longer possible. This person was clear. It was his frustration at being house-bound and dependent on visits from friends and family, rather than the physical symptoms of the cancer, that made him choose an elective death.

Palliative care is not a universal panacea. While this branch of medicine does have a valuable contribution to make, especially in the field of pain control, it is unhelpful to use symptom management as the benchmark against which a person's quality of life is measured.

Rather, people rate their quality of life in different ways with no two individuals' assessment the same. While a life without pain is clearly better than a life with pain, this is not always the most important issue. Instead it is that person's own complex assessment of their life's worth that is the key. The physical symptoms of an illness are often only one of many considerations. Just ask Angelique.

The Tired of Life Phenomenon

In recent years, a new trend has begun to emerge; one that has caused Exit to rethink our approach to death and dying. Increasingly at our workshops, we meet elderly people who are fit and healthy (for their age), but for whom life has become increasingly burdensome. Such people are not depressed. Rather, the sentiment expressed is that 'I have lived enough of the good life and now it's time to go.' The actions of Australian couple, Sidney and Marjorie Croft, explain this phenomenon well.

In 2002, the Crofts sent Exit International their suicide note explaining why they had decided to go together. Exit had no prior knowledge of the couple's plans. We knew only that they had attended several Exit workshops where they sat at the back, holding hands and asking questions.

The Crofts did not need to write this note yet they wanted us to understand. And in return they asked for our respect.

To Whom it May Concern

Please don't condemn us, or feel badly of us for what we have done.

We have thought clearly of this for a long time and it has taken a long time to get the drugs needed.

We are in our late 80s and 90 is on the horizon. At this stage, would it be wrong to expect no deterioration in our health? More importantly, would our mental state be bright and alert?

In 1974 we both lost our partners whom we loved very dearly. For two and a half years Marjorie became a recluse with her grief, and Sid became an alcoholic. We would not like to go through that traumatic experience again. Hence we decided we wanted to go together.

We have no children and no one to consider.

We have left instructions that we be cremated and that our ashes be mixed together. We feel that way, we will be together forever.

Please don't feel sad, or grieve for us. But feel glad in your heart as we do.

Sidney and Marjorie Croft

The Crofts are the private face of an increasingly common sentiment among a minority of older people; that is that a good life should be able to be brought to an end with a good death, when and if a person so wishes. To suggest, as many in the medical profession have done, that the Crofts were 'depressed' is to trivialise and patronise them for their actions.

Another person who evoked this 'tired of life' phenomenon was retired French academic, Lisette Nigot. In 2002, Lisette Nigot also took her own life, consuming lethal drugs she had stockpiled over the years. Lisette's reason for dying? She said she did not want to turn 80.

Lisette Nigot insisted that she had led a good and full life. She said she had always known that she would not want to become 'too old.' 'I do not take to old age very well' she told film-maker Janine Hosking whose feature documentary *Mademoiselle and the Doctor* traced the last months of her life.

In late 2002, shortly before her 80th birthday, Lisette Nigot ended her life. Intelligent and lucid to the end, Lisette knew her own mind. A fiercely independent woman, it is not surprising that she expected control in her dying, just as she had in her own life. In *Mademoiselle and the Doctor* she explained:

> *'I don't like the deterioration of my body ... I don't like not being able to do the things I used to be able to do ... and I don't like the discrepancy there is between the mind which remains what it always was, and the body which is sort of physically deteriorating.*
>
> *Perhaps my mind will go and I would hate that. And certainly my body will go and I wouldn't be very happy with that either. So I might as well go while the going is good'.*

When details of the Croft's and Lisette Nigot's death were made public, many tried to medicalize their situations. An assortment of diseases and conditions were suggested as reasons for their decision to end their lives. Underpinning all of this was the belief that 'well' people do not take their own life.

Mademoiselle Lisette Nigot

At Exit we do not encourage anyone, sick or well, to take their own life. We do, however, believe that a decision to end one's life can be rational. Such a decision can occur just as much in the context of age as in the context of serious suffering and disease. This is why all elderly people should have access to reliable end of life information; information which is critical if mistakes are to be prevented.

Conclusion

If one is to suggest that the elderly and seriously ill have the right - for good and sound reasons - to end their lives earlier than nature would have it, then the provision of accurate, up-to-date information is an important first step.

People want to know how to end their lives peacefully, reliably and with dignity. Most people know that they may never use this information. All are comforted, however, in knowing that if things 'turn bad' as they put it, they have a plan in place. Remember, suicide is legal, yet assisting a suicide is illegal. This is why everyone should develop an end of life plan. An end of life plan will keep one's family and loved ones safe from the law. An end of life plan is the responsible thing to do.